

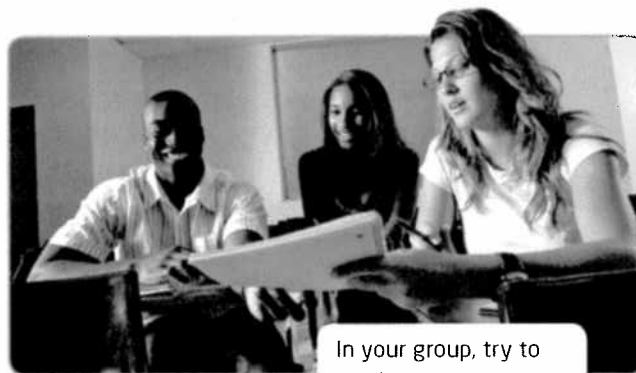
## Activity 1-2

### To Test or Not to Test?

Globally, Huntington disease affects about seven in 100 000 people, although some locations have a higher incidence than others. Genetic testing for a disease like Huntington raises many complex ethical issues. What kinds of issues might these be?

#### Procedure

1. Choose the perspective of a stakeholder in the debate about testing for Huntington disease. Suggested roles include the following:
  - You are a 30-year-old who has one parent with the disease. You are wondering whether to be tested.
  - You have just tested positive for the disease. You have a two-year-old child.
  - You are the owner of an insurance company considering a new client's application.
  - You are an employer. Your company invests heavily in employee training and generally counts on people staying with your company for many years or even decades.
  - You are a government official in charge of public health care. You are looking for ways to control costs.
2. Make a list of points to support your opinion using this textbook and your own ideas. Prepare a summary statement of your position.
3. In your role, discuss the questions that follow in a small group.
4. Share your ideas as a class.



In your group, try to reach a consensus on each question.

#### Questions

1. Should employers or insurance companies be allowed to require people to test for Huntington disease, or should taking the test be a matter of personal choice? Explain your answer.
2. Should people be required to reveal a family history of Huntington to a potential employer or insurance company? Or should such a matter be private?
3. Should children with a risk of Huntington disease be allowed to have the test? Why or why not?
4. Should health-care professionals discourage people with a risk of Huntington from having children? Explain your answer.
5. Should individuals pay to be tested, or should the public health-care system pay? How might this decision affect access to the test?
6. Should all stakeholders have an equal voice in decisions about genetic testing for Huntington disease? Explain your answer.

### DNA Screening in Canada

PKU, Down syndrome, and Huntington disease are not the only conditions that can be identified using DNA tests. For example, women can be screened for the presence of certain genes associated with breast cancer. Although only a small proportion of all breast cancers are due to genetic factors, the test could help women with the gene take preventative measures. Other conditions that can be determined with DNA screening include cystic fibrosis and spina bifida.